

Position Paper of The Arc of Pennsylvania with Respect to the Waiting List for People
with Mental Retardation (MR)
Adopted June 23, 2007

Background

The issue of people with intellectual disabilities waiting for community-based services is one of the most critical concerns facing individuals with disabilities and their families. According to the PA Waiting List Campaign (www.pawaitinglistcampaign.org), as of December 1, 2006, there were approximately 22,759 people on waiting lists across the Commonwealth in the community mental retardation system. The Waiting List for people with mental retardation has three levels: emergency, critical and planning.

- The emergency waiting list includes 3804 individuals who must be served *immediately* as a result of one of the following scenarios: the family is no longer able to provide care, emergency closure of a facility, current abuse investigation substantiated or other life threatening emergency situations regarding the individual receiving care.
- The critical lists includes 9676 individuals who will require supports within two years due to aging caregivers, increased behavioral support requirements, graduating high school or leaving a facility with an appropriate community alternative.
- The planning portion of the waiting list has 9279 individuals whose anticipated needs are more than two years away but less than five years from that time. This portion of the list also notes those where an aging caregiver is present, the person is losing eligibility for current services or accommodation, or may be graduating from high school.

The waiting list is made worse every year by virtue of several things. First, a lack of adequate annual funding or COLA (cost of Living Adjustment) to account for inflation results in service capacity being lost in order for providers to pay their bills. COLAs have not exceeded 2% in recent memory while home healthcare inflation rates range between 3-4%. Such COLAs have also only been targeted to staff salaries and do not address the overall costs of doing business. Second, initiatives to address the waiting list will continue to grow in an unpredictable fashion. Third, young people who have had the entitlement of special education though the age of 21 usually leave the special education system with little or no supports. Without the supports needed to maintain or improve their ability to function and thrive in the community, they quickly regress and their needs increase. Fourth, over 60% of people with mental retardation (adults and children) live with family members. Many are supported currently by family members age 70 and older. A large number of these elderly caregivers are widowed, caring for sick spouses or battling their own health issues. Without home modifications, ramps, lifts, beds, and transportation, most family caregivers are not able to provide adequate support for their loved one. Many single parents need day support so they can work to pay bills that keep their homes and family together. And, when the last caregiver in the family dies, a crisis emerges for the individual in need of supports and a place to live. Sadly, families will often not receive appropriate supports until their situations have become impossible to

manage. They eventually find their way to the emergency waiting list. For more information on the MR system, see www.dpw.state.pa.us./Disable/MentalRetardationServices)

The failure of state government to end the emergency waiting list and make a significant dent in ending the critical waiting list also has an adverse impact on people with intellectual disabilities still living in state-run institutions and large private Intermediate Care Facilities for people with Mental Retardation (ICF/MR). According to the US Supreme Court's *Olmstead* decision¹ (1999), it is unconstitutional to keep someone in a large institution unnecessarily. If community supports are not available because large waiting lists persist, it is unlikely that individuals living in large institutions will be offered an opportunity to return to their communities with an appropriate community-based supports. This is no excuse, and state government should have a plan to end unnecessary institutionalization while continuing to address the challenges of the waiting list.

Finally, there is another issue that advocates for people with mental retardation bring up occasionally, but often goes unaddressed. This involves those individuals who are unknown to the community system since they are not on any formally kept waiting lists. These individuals are sometimes referred to as the "shadow waiting list". This includes persons living with a caregiver who never registered for or requested services; those in rural communities, people who are in areas with heavy minority concentrations or other areas where information on community supports is not as widely known, due in part to cultural or language barriers; or individuals not known to the system but who are living in personal care homes, the criminal justice system, or are homeless. Cultural and language barriers, inadequate tracking of related data and limited community outreach may contribute to why individuals on the "shadow waiting list" are not known to the MR community or State Government.

The Arc of PA Position

The Arc of Pennsylvania supports a significant and sustained effort to end the emergency and critical waiting lists within a reasonable number of years. The current waiting list in the MR system often grows by about 100-200 individuals per month. The State Executive Branch should work with the General Assembly and stakeholders of the community MR system to develop a waiting list plan that commits to ending the emergency waiting list in 2 years and ending the critical waiting list in 5 years. The Arc of Pennsylvania supports the inclusion of a real COLA (Cost of Living Adjustment) annually to account for stem inflation so as to help curb the growth of the waiting list through service capacity loss. This COLA would be equal to the CMS (Centers for Medicare & Medicaid) HHMBI (Home Health Market Basket Index), or the rate of home healthcare inflation, which has ranged from 3-4% recently, allowing providers to receive sufficient allocations to cover the entire cost of doing business.

Next, in terms of planning for an individual's adult life, resources should be dedicated to supporting young adults leaving the special education system. The Arc of PA supports the initiation of transition planning for young people with intellectual disabilities at age

14. This gives the individual the best chance of success in their transition to adult life endeavors, thus reducing the likelihood that they will end up on the emergency or critical waiting list. The waiting list plan should incorporate the *Olmstead* test by asking first what is needed for that individual to be integrated into their community. This will require greater capacity building and support for cutting edge self-determination services in the least restrictive environment (LRE). Independent living, life-sharing, and supported employment should be strongly encouraged. Finally, ODP must determine how to adequately address the “shadow waiting list” through utilization of improving targeted outreach, better tracking of data and addressing cultural and language barriers, particularly in rural and minority communities.

The reduction and gradual elimination of the MR Waiting List can best be achieved through joint collaboration of advocates, providers, friends, families, informal supports, self-advocates and branches of governmental sectors of the community. The Arc of PA and its members stand ready to work with all stakeholders involved with the waiting list to make Pennsylvania a better place to life, work, and play for people with mental retardation and their families.

¹ *Olmstead* refers to the US Supreme Court decision in 1999 (*L.C. & E.W. v. Olmstead*) that interpreted the Americans with Disabilities Act (ADA) to mean that states must provide services in the most integrated settings appropriate to the needs of qualified individuals with disabilities. The ruling directs states to make “reasonable modifications” in programs and activities. As a result, the federal government has encouraged states to plan for reforms not only in the health arena but also in the areas of transportation, housing, education and other social supports to integrate people with disabilities in the least restrictive environment possible. At this time, the Commonwealth of Pennsylvania is not known to have a public plan regarding the implementation of *Olmstead*. (www.ncsl.org/programs/health/forum/olmsreport.htm)